

The background of the slide features a row of black silhouettes of eight people standing with their backs to the viewer. Behind them is a detailed silhouette of a city skyline, including several prominent skyscrapers. The entire scene is set against a solid blue background.

Public Participation and Community-Based Participatory Research

Tuesday, June 22, 2004
EPA Expert Technical Review Panel
St. John's University

The background of the slide features a blue sky with a city skyline, including several tall skyscrapers. In the foreground, there are black silhouettes of a group of people, including men and women of various ages and ethnicities, some wearing hard hats. The text is overlaid on this image.

This presentation is the result of a Community meeting held on June 17, 2004.

Marcia Pinkett-Heller, an expert in Community-Based Participatory Research (CBPR), helped to facilitate the meeting.

The top of the slide features a black silhouette of a group of people's heads and shoulders, positioned in front of a blue sky with a white city skyline. The skyline includes several prominent skyscrapers.

Community-Based Participatory Research (CBPR)

Presentation Overview

- 1) What CBPR Is
- 2) The Benefits of CBPR
- 3) CBPR and EPA Policy
- 4) Why CBPR is Needed in the Panel Process
- 5) Community Concerns About Current Process
- 6) Community Concerns About Current Content
- 7) Community Requests

The top of the slide features a graphic with black silhouettes of several people's heads and shoulders in the foreground. Behind them is a city skyline with various skyscrapers under a clear blue sky. The title text is overlaid on this graphic.

Community-Based Participatory Research (CBPR): What It Is

- A formal mechanism for community input into the design and conduct of project protocols and research
- Formalizes response to community concerns
- Ensures those most affected by the decisions, i.e., the community, have a say in the decision-making process
- Ensures the conceptualization, design and implementation of the protocols and research are reflective of community needs
- Community accepted as a partner, rather than a subject
- Recognizes community strengths and expertise
- Ensures more broad-based representation in decisions

Note: For the purpose of the WTC Expert Technical Review Panel, CBPR applies to all aspects of the Panel's deliberations, not just those elements that are deemed as strictly "research".

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Community-Based Participatory Research (CBPR): What the Benefits Are

- Facilitates meaningful dialogue between the Community and the Panel
- Allows for more cohesive input by the Community to the Panel
- Enables the Community to call upon appropriate experts when technical issues under discussion require Community input
- Helps determine which issues are subject to a technical review
- Provides critical information and perspective from the Community
- Increases trust and acceptance of the process and decisions
- Incorporates unique cultural factors into intervention strategies
- Increases the capacity of the project/research implementation by adding the Community as a resource
- Facilitates the dissemination of information to the Community in useful terms

The top of the slide features a horizontal banner. It contains black silhouettes of seven individuals wearing uniforms with peaked caps, standing in a row. Behind them is a grayscale image of a city skyline with various skyscrapers under a clear blue sky. The title 'CBPR and EPA Policy' is centered in white text over the silhouettes.

CBPR and EPA Policy

CBPR is consistent with EPA's Public Involvement Policy.

CBPR is also utilized by other government agencies, e.g., the National Institute for Environmental Health Sciences (NIEHS) and the Agency for Healthcare Research and Quality (AHRQ).



CBPR and EPA Policy

Seven basic steps for effective public involvement in any EPA decision or activity are the EPA Public Involvement Policy's core ¹:

1. Plan and budget for public involvement
2. Identify the interested and affected public
3. Consider providing technical or financial assistance to the public to facilitate involvement
4. Provide information and outreach to the public
5. Conduct public consultation and involvement activities
6. Review and use input and provide feedback
7. Evaluate public involvement

¹ Public Involvement Policy of the U.S. Environmental Protection Agency, May 2003, EPA 2330B-03-002.



Community-Based Participatory Research (CBPR): Why It Is Needed in the WTC Expert Technical Review Panel Process

The Community is dissatisfied with the:

1. current process for public participation and;
2. the course of the current, proposed strategies (content).



Community Concerns About Current Panel Process

- Current process does not facilitate meaningful input by the Community
- Current process does not facilitate meaningful responses to the Community's concerns
- Process concerns must be addressed because they impact decisions and outcomes that directly affect the Community



Community Concerns About Current Panel Process

- Single Community Liaison on the Panel tasked with quickly assimilating and disseminating complex information to the “Community” at large, eliciting feedback and then synthesizing and communicating the “Community’s” concerns to the Panel
- Issue above is compounded when the ex-officio Community Liaison is asked to join a technical discussion at the last minute
- Time is not allotted for discussion of the Community Liaison presentations
- Meeting transcripts are not provided for the Panel members or the Community
- The Panel does not respond to public comments
- Panel agendas and public comments are not posted in a timely manner
- No clear, transparent Panel process



Community Concerns About Content

- The validation of a WTC signature is a research project
- This Panel is not a peer review panel on research such as dust signature
- The WTC signature research is not needed to identify contaminants
- The WTC signature research is not needed to develop appropriate sampling and clean-up protocols
- The development of appropriate sampling and clean-up protocols should not be delayed until the WTC signature research is completed (Spring '05 proposed for peer review in timeline)
- The development of a WTC signature has major policy implications which have not been addressed and cannot be ignored
- There has been no discussion by the Panel about unmet public health needs



What the Community Wants

- The EPA must conduct comprehensive and representative testing for a range of contaminants including, but not limited to, the already identified Contaminants of Potential Concern (COPCs)
- Testing should be conducted in concentric circles radiating outward from the WTC site and should include areas known to have been impacted by the plume and/or to have experienced negative health effects, (e.g., north of Canal St. and downtown Brooklyn)
- Special attention should be paid to underserved communities, such as Chinatown



What the Community Wants

- Testing should be conducted in spaces that have NOT been cleaned by the EPA, as well as, spaces that have been cleaned by the EPA
- Testing should be conducted in non-residential locations, (e.g., workplaces, public spaces), as well as, residential locations
- An emphasis should be placed on environmental sampling within mechanical ventilation systems
- A comprehensive plan should be developed to protect against WTC-related contamination created by on-going demolition, renovation, and construction activities
- A clean-up plan should be developed for contaminated spaces that utilizes known health-based benchmarks and/or background levels, whichever is more protective of the public's health



Community Requests

The Community would like a written response from the Chair to the following requests, in advance of the next Panel meeting:

- An agreement to formally incorporate CBPR into the WTC Expert Technical Review Panel process and a timeline for implementation of CBPR
- Funding to be provided for an experienced CBPR facilitator, chosen by the Community
- Funding to be provided for the Community to obtain technical consultants as needed, chosen by the Community
- The discussion of unmet public health needs to begin at the next scheduled Panel meeting, with presentations by mutually agreed upon medical and public health experts
- An agreement the WTC signature research will not delay the onset of a testing and clean-up program